



**California Health & Human Services Agency
Data Exchange Framework Stakeholder Advisory Group
Meeting #2 (Oct. 7, 2021) Pre-Read Materials**

For Discussion: Data Exchange Scenario Examples

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Developed by Manatt Health Strategies

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Introduction

This document introduces six scenarios - a potential event, combination of events, or set of activities that would require the exchange of health and/or human service information between actors to ultimately support Californians' health and wellbeing - for Stakeholder Advisory Group consideration and discussion through the Data Exchange Framework development process. Examining scenarios through the DxF development process will allow us to:

- Identify shortcomings of our current system of electronic information exchange; and,
- Develop policy, program, and fiscal recommendations and actions that can be incorporated into the Data Exchange Framework to overcome barriers.

The six scenarios include:

1. **Acute or Chronic Health Needs:** Addressing the health and social needs of individuals with acute or chronic care needs.
2. **Complex Health & Social Needs:** Addressing the health and social needs of individuals with complex medical and behavioral health conditions and social needs.
3. **Population Health & Value-Based Care:** Addressing the health and social needs of individuals and populations across the continuum of care using data driven risk stratification, predictive analytics, identifying gaps in care and standardized assessment processes.
4. **Emergency Responses:** Addressing the health and social needs of individuals and populations by ensuring that emergency response providers and disaster healthcare volunteers have access to patients' clinical records and other relevant information during emergencies.
5. **Public Health Responses:** Addressing the health and social needs of Californians by strengthening public health surveillance, research, preparedness, and response to public health emergencies.
6. **Coordinating Reentry Health Services:** Addressing the health and social needs of individuals as they transition from incarceration back into their communities.

Each scenario has been illustrated by an example of how it may unfold, including:

1. Illustration or "story," from an individual's perspective, as he/she/they confront a triggering adverse event and engage with Actors who are required to exchange information to address the individual's needs;
2. Summary of the key data exchange challenges Actors confront when striving to meet the individual's needs.

These scenarios are intended to surface the most pressing data exchange needs, existing gaps, and barriers, and guide the development of policy and program Data Exchange Framework recommendations. They represent simplified illustrations and are

not intended to be a comprehensive inventory of all possible actors, data exchanges and challenges that exist within a given scenario.

Scenario 1: Coordinating Care for Individuals with Acute or Chronic Health Needs

1. Description

Addressing the health and social needs of individuals with acute or chronic care needs.

2. Current State and Illustrative Example:

Many individuals receive health care from multiple unaffiliated providers resulting in care coordination challenges. Despite widespread adoption of electronic health records, there remain significant barriers to seamless exchange of data to effectively coordinate care.¹

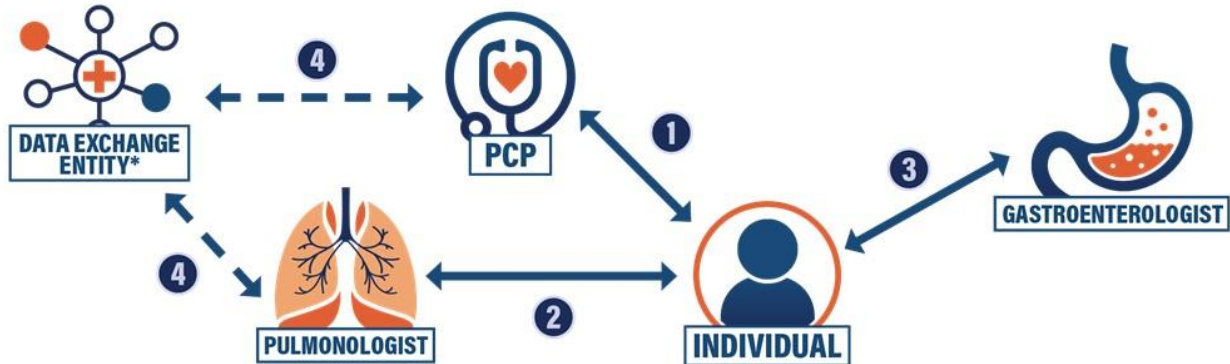
Illustrative Example

A 70-year-old woman is undergoing treatment for hypertension and chronic obstructive pulmonary disease (COPD). She is referred to a specialist following persistent gastrointestinal distress where she is newly diagnosed with inflammatory bowel disease (IBD). She begins to receive treatment from a gastroenterologist in addition to the care she continues to receive from her primary care provider (PCP) and pulmonologist. None of the three providers practice in the same health system nor participate in a common provider network. The PCP and the pulmonologist use a common EHR system that allows for data exchange. Shared participation in the EHR Vendor Network allows the two providers to access the individual's progress notes and medication information across both practices to inform care plans and avoid contraindicated care.

However, the gastroenterologist is a solo practitioner and does not participate in the EHR Vendor Network nor in any Health Information Organization or national network. Instead, the gastroenterologist shares information with other providers primarily using faxed documents and ad hoc phone conversations. As a result, the gastroenterologist has incomplete information and isn't able to share complete patient records the patient's PCP or pulmonologist. The patient spends large portions of provider visit time relaying information about treatment received in other settings. However, she has trouble recalling her treatment plan, prescribed medications and other details that result in an increased risk of adverse medication interactions and delaying care as their providers struggle to develop a comprehensive care plan that incorporates all of their health needs.

¹ Fewer than half of U.S. primary care providers reported being able to receive information from specialists about changes to patients' medications or care plans, according to one international survey. The Commonwealth Fund. 2019 Commonwealth Fund International Health Policy Survey of Primary Care Physicians. December 2019. <https://www.commonwealthfund.org/publications/surveys/2019/dec/2019-commonwealth-fund-international-health-policy-survey-primary>

Illustration



*Data Exchange Entity may include a HIO, national network, EHR vendor network, or other data exchange entity

Data Exchange & Process Steps

1. Individual engages primary care provider (PCP) for treatment of hypertension and general health needs
2. Individual engages pulmonologist (specialist) for treatment of COPD
3. Individual engages gastroenterologist (specialist) for treatment of IBD
4. Select health providers are engaged in data sharing with a data exchange entity

Illustration Actors and Roles

Actor	Roles Specific to the Example
Individual	<ul style="list-style-type: none"> • Receives treatment for chronic conditions from three unaffiliated providers
Primary Care Provider	<ul style="list-style-type: none"> • Treats the individual's general health needs, including their hypertension • Coordinates care across providers
Specialty Provider - Pulmonologist	<ul style="list-style-type: none"> • Treats the individual's COPD • Coordinates care across providers
Specialty Provider - Gastroenterologist	<ul style="list-style-type: none"> • Treats the individual's IBD • Coordinates care across providers
EHR Vendor Network	<ul style="list-style-type: none"> • Facilitates the exchange of health information between the individual's PCP and pulmonologist

3. Key Challenges

The following challenges were identified for this Scenario:

- 1. Gaps in Data Infrastructure:** While overall adoption of electronic data infrastructure has grown significantly over the last two decades, technological gaps persist for some sectors and actors. For example, while 96% of non-federal acute care hospitals possessed certified EHR technology in 2015, over 10% of

office-based physicians did not possess any EHR system.^{2,3} Some behavioral health, long-term and post-acute care and safety-net providers face particular challenges – primarily financial and technical – when adopting technical infrastructure to share data with other entities that provide care for the same individuals. For example, in 2017, only two-thirds of skilled nursing facilities reported using an EHR.⁴ Gaps in infrastructure also exist across geographies with up to 19 of California’s 58 counties having no HIO to support data exchange.⁵

2. Barriers to Data Exchange: Availability of data infrastructure does not guarantee ability to exchange usable data. For example, in 2018, fewer than half of non-federal acute care hospitals reported being able to find patient health information, and send, receive, and integrate patient summary of care records from sources outside their health system.⁶ Barriers to effective data exchange include lack of interoperability between EHRs (particularly among providers using non-certified EHR technologies), challenges with individual and provider identity matching, and absence of key data types.

3. Restrictions on the Transmission of Certain Data Types: Certain data types, including behavioral health (e.g., mental health, substance use disorder), HIV/AIDs test results, and some sexual health information, are governed by specific federal and state rules and regulations and require consent procedures that may complicate automated exchange.

² Centers for Disease Control and Prevention. 2019 National Electronic Health Records Survey Public Use File National Weighted Estimates. National Center for Health Statistics. August 2021. <https://www.cdc.gov/nchs/nehrs/about.htm>

³ Henry, JaWanna, et al. Adoption of Electronic Health Record Systems among U.S. Non-Federal Acute Care Hospitals: 2008-2015. The Office of the National Coordinator for Health Information Technology. May 2016. https://www.healthit.gov/sites/default/files/briefs/2015_hospital_adoption_db_v17.pdf

⁴ Henry, JaWanna, et al. Electronic Health Record Adoption and Interoperability among U.S. Skilled Nursing Facilities and Home Health Agencies in 2017. The Office of the National Coordinator for Health Information Technology. November 2018. <https://www.healthit.gov/sites/default/files/page/2018-11/Electronic-Health-Record-Adoption-and-Interoperability-among-U.S.-Skilled-Nursing-Facilities-and-Home-Health-Agencies-in-2017.pdf>

⁵ Elson, Mark. Health Information Exchange in California: Overview of Network Types and Characteristics. California Health Care Foundation. August 2021. <https://www.chcf.org/wp-content/uploads/2021/02/HIECAOverviewNetworkTypesCharacteristics082021.pdf>

⁶ Pylypchuk, Yuriy, et al. State of Interoperability among U.S. Non-federal Acute Care Hospitals in 2018. The Office of the National Coordinator for Health Information Technology. March 2020. <https://www.healthit.gov/sites/default/files/page/2020-03/State-of-Interoperability-among-US-Non-federal-Acute-Care-Hospitals-in-2018.pdf>

Scenario 2: Serving Individuals with Complex Health and Social Needs

1. Description

Addressing the health and social needs of individuals with complex medical and behavioral health conditions and social needs.

2. Current State and Illustrative Example

Individuals with complex health and social needs receive care from a broad spectrum of unaffiliated primary care, specialty care, behavioral health, and social service providers, each providing services to address specific needs of an individual.

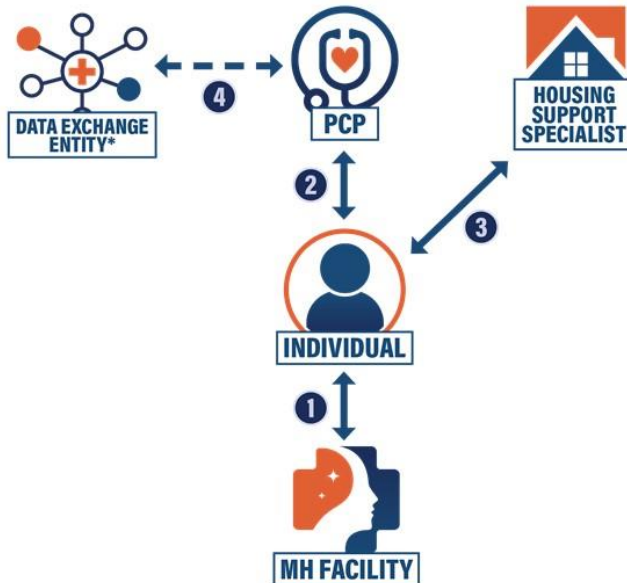
Illustrative Example⁷

A 40-year-old Latino male with a diagnosis of schizophrenia and diabetes who is also experiencing housing instability, is admitted to a mental health facility following an acute episode of schizophrenia. The mental health facility does not have a certified EHR or connect to a HIO, national network, EHR vendor network or other data exchange entity. As a result, providers at the mental health facility are unable to view the individual's physical health record and remain unaware of their diabetes and whether the individual has a regular primary care physician. The individual's primary care physician has a certified EHR that is connected to a HIO, but she is unaware of the individual's admission to a mental health facility and is unable to coordinate care and support the development of a treatment plan.

The housing support specialist at the CBO that supported the individual in finding temporary housing remains unaware of the individual's hospitalization. After several failed attempts to contact the individual to renew their housing placement, the housing support specialist suspends further outreach efforts and the individual loses their source of housing. Since the providers at the mental health facility do not have access to the individual's housing information, both they and the patient are unaware that the individual no longer has a place to live, and they discharge the patient once stabilized. The individual is forced to reside at a homeless shelter while they attempting to reengage with the housing support specialist to renew their housing placement. The shelter does not have a refrigerator for the individual to store their insulin, putting them at greater risk of acute and long-term complications from diabetes.

⁷ Scenario based on a scenario originally developed for a California Health Care Foundation Issue Brief: [Why California Needs Better Data Exchange: Challenges, Impacts, and Policy Options for a 21st Century Health System](#).

Illustration



- | Data Exchange & Process Steps |
|--|
| 1. Individual is admitted to a mental health (MH) facility to receive treatment for psychiatric symptoms |
| 2. Individual engages PCP for treatment of diabetes |
| 3. Individual engages housing support specialist to secure safe, affordable housing |
| 4. Select health providers are engaged in data sharing with a data exchange entity |

*Data Exchange Entity may include a HIO, national network, EHR vendor network, or other data exchange entity

Illustration Actors and Roles

Actor	Roles Specific to the Example
Individual	<ul style="list-style-type: none"> Receives treatment for psychotic episode at mental health facility
Health Information Organization (HIO)	<ul style="list-style-type: none"> Exchanges clinical and event notification information with the primary care provider
Hospital: Mental Health Facility	<ul style="list-style-type: none"> Treats individual's schizophrenia
Primary Care Physician	<ul style="list-style-type: none"> Treats individual's diabetes Exchanges clinical data with HIO
Community Based Organization (CBO): Housing Support Specialist	<ul style="list-style-type: none"> Supports individual in finding access to affordable housing options
Pharmacy	<ul style="list-style-type: none"> Dispenses prescriptions to individual

3. Key Challenges

The following challenges were identified for this Scenario:

- 1. Gaps in Data Infrastructure:** Behavioral health and many small and other under-resourced safety-net providers often lack technical infrastructure – including certified EHR technology – capable of exchanging clinical and behavioral health data with other providers to support care management and coordination.⁸ Further, not all providers with a certified EHR technology are

⁸ Twenty Whole Person Care (WPC) pilots (80 percent) reported difficulty implementing planned data-sharing systems or integrating health and human services data, and twelve pilots (48 percent) identified data sharing as one of the biggest barriers to implementing WPC. Chuang, Emmeline, et al. "Integrating Health And Human Services In California's Whole Person Care Medicaid 1115 Waiver Demonstration: An overview of a California demonstration program focused on improving the integrated delivery of health,

connected or have access to an HIO, or actively engage in cross-sector data sharing. CBOs that provide housing support and other services often do not have technologies or platforms to share and receive social or health information with other providers.

2. Absence of Key Data Types: National networks, HIOs, and EHRs generally have limited capabilities to exchange SDOH data, including housing data. Closed loop referral networks and emerging community information exchanges (CIEs) efforts (e.g., Alameda County Care Connect and CIE San Diego), are able to share some SDOH data but are not widespread across California.

3. Complex Data Exchange Rules and Regulations: Many federal and state laws, regulations and policies that govern the exchange of physical, behavioral health, and social services data can create real or perceived barriers to sharing information that is necessary to inform the care of individuals with complex health and social needs. They can create challenges for consent management by imposing a variety of consent processes and timeframes to share an individual's data.⁹ For example, behavioral health data is protected by 42 C.F.R. Part 2, which requires the individual's written authorization to share data; however, the lack of robust consent management systems and processes hampers data sharing.

behavioral health, and social services for certain Medicaid beneficiaries." Health Affairs. April 2020, pp 639-648.

⁹ Sixteen WPC pilots (64 percent) identified patient privacy and confidentiality regulations as a major root cause of these barriers, and nine pilots explicitly referred to Title 42 of the Code of Federal Regulations, Part 2, as complicating efforts to share data on substance abuse treatment. Ibid.

Scenario 3: Population Health & Value-Based Care

1. Description

Addressing the health and social needs of individuals and populations across the continuum of care using data driven risk stratification, predictive analytics, identifying gaps in care and standardized assessment processes.

2. Current State and Illustrative Example

Healthcare organizations are increasingly being held accountable for managing the health of their broad and diverse populations (i.e., members and patients), a responsibility reflected in their contracting, payment arrangements, and their health information technology and health information exchange needs and investments.

Illustrative Example

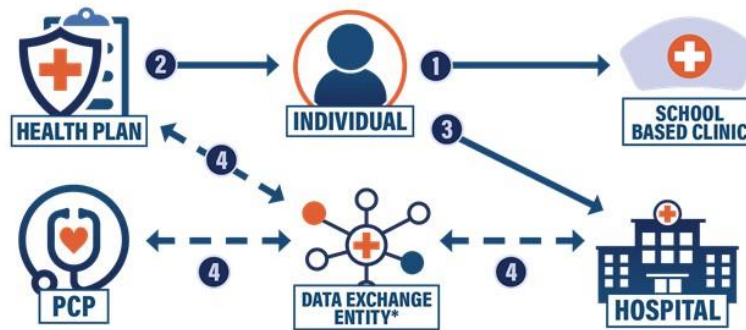
An African American, teenage non-binary child with undiagnosed asthma has health coverage through a commercial health plan, but they do not have a primary care provider. Their asthma has been managed largely independently through lifestyle changes such that their condition has not required the need for medical intervention. As a result, their health plan has no medical claims on file that would document their chronic condition and as such does not identify them as being at risk. However, during a recent wildfire, ambient smoke persists in their community, the subsequent local power outages limit their access to indoor air conditioning, worsening their asthma symptoms.

While at school, they visits the nurse who documents their symptoms and refers them to a primary care provider. Their health plan remains unaware of their symptoms because it does not receive data information from their school-based provider. While their health plan's population health management platform signals that individuals in their neighborhood with asthma conditions might be at risk due to a declared emergency involving a wildfire, it does not notify the minor's family given the lack of historical information about their asthma. Additionally, the health plan does not know that the individual is African American, which may put them at higher risk for asthma complications.¹⁰

The individual does not end up going to the primary care provider because their office is far from where they live, and they are concerned that the PCP may not be accepting of their gender identity. Without the medications they needs, their condition worsens, and they are taken to a local emergency department for treatment.

¹⁰ U.S. Department of Health and Human Services Office of Minority Health. Asthma and African Americans. February 2021. <https://minorityhealth.hhs.gov/omh/browse.aspx?lvl=4&lvlid=15>

Illustration



Data Exchange & Process Steps

1. Child engages school nurse due to asthma exacerbation; child referred to PCP, but does not go due to distance and discrimination concerns (not shown)
2. Health plan’s population health management system identifies individuals with asthma in the child’s neighborhood as being at risk, but plan is not aware of child’s symptoms or recent school-based clinic visit
3. Child admitted to local emergency department after symptoms worsen
4. Select health providers are engaged in data sharing with a data exchange entity

**Data Exchange Entity may include a HIO, national network, EHR vendor network, or other data exchange entity*

Illustration Actors and Roles

Actor	Roles Specific to the Example
Individual	<ul style="list-style-type: none"> • Presents symptoms and seeks care
Health Plan	<ul style="list-style-type: none"> • Provides coverage for health events • Aggregates and analyzes data to identify member needs • Provides care coordination support based on identified member needs
School Nurse	<ul style="list-style-type: none"> • Documents symptoms and provides care • Sends referrals and information to other entities, as applicable
Hospital (Emergency Department)	<ul style="list-style-type: none"> • Documents symptoms and provides care • Sends referrals and information to other entities, as applicable
Primary Care Provider	<ul style="list-style-type: none"> • Documents symptoms and provides care • Sends referrals and information to other entities, as applicable

3. Key Challenges

Slow and uneven progress towards seamless health data interoperability hinders healthcare organizations ability to access the data they need population health management activities including risk stratification, assessments, identification in gaps in care and cultural competency. A survey conducted by the American Hospital Association found that adoption of population management tools has been hampered by data acquisition, aggregation and interoperability challenges. As a result, payers and providers have difficulty identifying gaps in care, generating actionable insights into

value-based care, and comparing quality and performance to evidence-based standards.¹¹

Specific data-related challenges include:¹²

1. Gaps in Data Infrastructure and Exchange Capabilities: Lack a certified EHR or systems at a variety of setting, including with school-based health providers, that are capable of storing and readily sharing electronic data with other providers, health plans, or other actors.

2. Absence of Key Data Types: Critical data types, particularly information on race, ethnicity, language, sexual orientation, and gender identity, that could inform population health and equity efforts are challenging to acquire.¹³ Recent reports found that every three commercial health plans had race data missing for over 50 percent of their member populations, and half of Medicaid health plans face the same data gaps.¹⁴ In addition, health plans often rely on administrative data from claims to inform care management decisions at the individual level and approaches at the population level. Without access to timely physical, behavioral health, and SDOH data, health plans and ACOs cannot integrate important information into risk stratification algorithms and population health management programs, and have limited ability to detect and address disparities in outcomes, identify best practices, develop new innovative payment models, and organize and manage high-quality provider networks.

3. Complex data exchange rules and regulations: Federal and state laws, regulations and policies as they pertain to minors can be complex and may create hesitancy to share data.

¹¹ Bresnick, Jennifer. Data Exchange, Integration Shortfalls Stymie Population Health. Health IT Analytics. November 2018. <https://healthitanalytics.com/news/data-exchange-integration-shortfalls-stymie-population-health>

¹² Frohlich, Jonah, et al. Why California Needs Better Data Exchange: Challenges, Impacts, and Policy Options for a 21st Century Health System. California Health Care Foundation. March 2021. <https://www.chcf.org/wp-content/uploads/2021/02/WhyCaliforniaNeedsBetterDataExchange.pdf>

¹³ McAvey, Kevin and Alisha Reginal. Unlocking Race and Ethnicity Data to Promote Health Equity in California. Manatt Health. April 2021. <https://www.manatt.com/insights/white-papers/2021/unlocking-race-and-ethnicity-data-to-promote-health>

¹⁴ Waddill, Kelsey. How to Overcome Challenges in Gathering Racial, Ethnicity Data. HealthPayerIntelligence. April 2021. <https://healthpayerintelligence.com/news/how-to-overcome-challenges-in-gathering-racial-ethnicity-data>

Scenario 4: Supporting Emergency Responses

1. Description

Addressing the health and social needs of individuals and populations by ensuring that emergency response providers and disaster healthcare volunteers have access to patients' clinical records and other relevant information during emergencies.

2. Current State and Illustrative Example

During emergencies and disasters, emergency response providers and other first responders, disaster healthcare volunteers, and emergency departments seek access to health and social service information that are needed to support care for individuals who are impacted by the emergency.

During disasters, **California's Patient Unified Lookup System for Emergencies (PULSE)** allows certain types of registered disaster healthcare volunteers to view clinical summaries that include patient records for allergies, problem lists, and medications to inform clinical decision making.¹⁵

During emergencies, California's **Search, Alert, File, and Reconcile (SAFR)** process enables emergency response providers on the scene to electronically query participating HIOs or hospitals for an individual's health information, alert the receiving emergency department of the patient and their condition prior to arrival, deliver a record of the treatment provided to the receiving hospital's EHR, and, following discharge or transfer of the individual, receive key information on patient outcomes from the hospital.^{16,17}

Illustrative Example¹⁸

A 50-year-old adult male with a diagnosis of chronic heart disease who receives Supplemental Nutrition Assistance Program benefits through CalFresh and is eligible for medically tailored meals through their managed care plan is evacuated from a wildfire. The man is disoriented and seeks care from a disaster healthcare volunteer at an alternative care facility near the evacuation center.

In his haste to evacuate, he was unable to bring his medications, CalFresh benefit card, or medical insurance card. Since the local clinic where he receives most of his care was

¹⁵ California Emergency Medical Services Authority. Health Information Exchange.

<https://emsa.ca.gov/hie/>

¹⁶ California Emergency Medical Services Authority. Use of Electronic Health Records (EHRs) and Connections to Other Systems. April 2021. <https://hieinemsinca.files.wordpress.com/2021/04/emsa-dhcs-workshop-2-a-april-20-2021-lwr-final-4-19-1.pdf>

¹⁷ California Emergency Medical Services Authority. Health Information Technology for EMS Project. October 2018. <https://emsa.ca.gov/wp-content/uploads/sites/71/2018/10/California-HIE-for-EMS-CAHIE-Webinar-10-2018.pdf>

¹⁸ Scenario based on a scenario originally developed for a California Health Care Foundation Issue Brief: [Why California Needs Better Data Exchange: Challenges, Impacts, and Policy Options for a 21st Century Health System](#).

closed down in the fire and the disaster healthcare volunteer does not have access to his medical record, responders must rely on the disoriented man to explain his conditions and medications.

The patient mentions that he takes medication for chronic heart disease, but does not remember the medication’s name, dosage, or time of his last dose. He also forgets to mention that he receives medically tailored meals to help manage his heart disease, and, since he forgot his medical insurance card, the disaster healthcare volunteer does not have any way of knowing or helping his restart their meal plan. The disaster healthcare volunteer consults with an emergency response provider who queries PULSE, but no records are found given that the patient received medication from a clinic that was not connected to a hospital or HIO. Unsure of the severity of the patient’s symptoms, he is transported to an overwhelmed local emergency department as a precaution. The patient is diagnosed and restarts his medication after his emergency department visit.

Throughout the experience, physical health providers did not have access to the patient’s social service information and remained unaware that they were a CalFresh beneficiary. Several opportunities to reconnect the individual with services were missed, as the onus of renewing CalFresh benefits falls on the individual who is otherwise focusing on addressing his chronic heart disease and recovering from being temporarily displaced by the fire.

Illustration



Data Exchange & Process Steps
1. Individual is disoriented and seeks care from disaster healthcare volunteer
2. Disaster healthcare volunteer queries PULSE and SAFR (not shown) to view individual's available clinical summaries
3. Individual is transferred to a hospital emergency department (ED) for further assessment
4. Individual engages with ED physician to receive treatment for chronic heart condition
5. Some actors are potentially disconnected from information exchange

Illustration Actors and Roles

Actor	Roles Specific to the Example
Individual	<ul style="list-style-type: none"> Receives treatment for chronic heart disease from disaster medical provider and at emergency department Receives CalFresh benefits
Hospital: Emergency Department	<ul style="list-style-type: none"> Treats individual's chronic heart disease
Alternative Care Facility: Disaster Healthcare Volunteer	<ul style="list-style-type: none"> Queries PULSE for individual's medical record, Transfers individual to emergency department
Community Clinic	<ul style="list-style-type: none"> Treats individual's chronic heart disease prior to the wildfire
Managed Care Plan	<ul style="list-style-type: none"> Authorizes medically tailored meals benefit
State Government Departments: Department of Social Services	<ul style="list-style-type: none"> Supervises CalFresh program
County Government Departments: Welfare Departments	<ul style="list-style-type: none"> Administers CalFresh program
PULSE	<ul style="list-style-type: none"> Queried for Individual's medical record

3. Key Challenges

While PULSE and SAFR provide important data exchange functions for emergency response providers and disaster healthcare volunteers during disasters and personal health emergencies in California, there several challenges remain:

1. Gaps in Data Infrastructure: For both PULSE and SAFR gaps remain in emergency response and disaster healthcare providers' access to critical physical health records. PULSE is operational across all counties in the state and all of California's regional HIOs participate in PULSE; however, some hospitals don't connect to PULSE, either through an HIO or directly to the PULSE service. SAFR, as of April 2021, was active in 29 of California's 58 counties and connected with eight HIOs, 70 emergency response organizations, and 50 receiving hospitals (specifically for the search and reconcile functions).¹⁹

2. Absence of Key Data Types: Neither PULSE nor SAFR currently collect or exchange non-clinical SDOH data, potentially creating challenges in ensuring the continuity coordination of social services for individuals who are impacted by a disaster or other personal health emergency.

3. Complex data exchange rules and regulations: Federal and state law in some instances may prohibit the exchange of SDOH data. In this instance, medically tailored meal providers subject to USDA rules may not disclose Member information with entities other than those directly connected with the administration of the applicable USDA program or public agencies operating

¹⁹ California Emergency Medical Services Authority. Use of Electronic Health Records (EHRs) and Connections to Other Systems. April 2021. <https://hieinemsinca.files.wordpress.com/2021/04/emsa-dhcs-workshop-2-a-april-20-2021-lwr-final-4-19-1.pdf>

under contract with the state's SNAP or WIC agency. This interpretation of these rules can create challenges for consent management by imposing a variety of consent processes and timeframes to share an individual's data, which can be impossible to sort through during an emergency.

Scenario 5: Supporting Public Health Responses

1. Description

Addressing the health and social needs of Californians by strengthening public health surveillance, research, preparedness, and response to public health emergencies.

2. Current State and Illustrative Example

In support of public health, information exchange plays a critical role for:

- Disease surveillance
- Reporting, tracking, and response (e.g., lab result reporting and case reporting)
- Resource availability and utilization (e.g., personal protective equipment, hospital bed availability)
- Epidemiological investigation (e.g., contact tracing)
- Vaccine and immunization management (e.g., distribution and tracking of administration)
- Outbreak management of infectious and chemical exposures
- Laboratory, medical, nursing and other clinical consultation and direct clinical management for pathogens that are new (COVID), drug resistant (multi-drug resistant TB), or those that pose a threat to a broader community (chemical toxicity in public pools)

With timely access to testing information from laboratories, providers, and hospitals, public health concerns (e.g., disease clusters) can be quickly identified and used to inform decisions on allocation of critical resources (e.g., ICU beds, ventilators) and rapidly manage outbreaks and toxic exposures. Reliable and timely information regarding statewide testing, contact tracing, isolation support, clinical consultation and management and vaccination administration programs supports the ability of the state, counties, cities, and health system to organize and coordinate public health efforts.

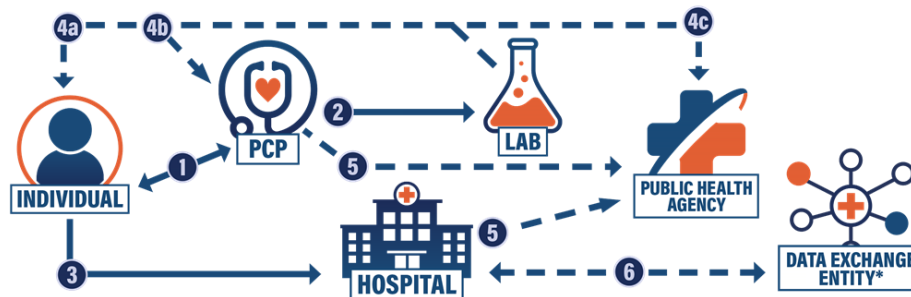
Illustrative Example

A 35-year-old Asian-American woman in Los Angeles County works as a housecleaner and lives in a multi-generational setting with her husband, three children, and parents. She begins to exhibit symptoms associated with the onset of COVID-19, including a fever, fatigue, and body aches. She contacts her primary care physician, who directs her to a COVID-19 test site and recommends that she self-quarantine and monitor her condition. The patient gets tested and restricts her activities but has to leave her apartment to get food at a grocery store.

While awaiting test results, her condition declines, with a worsening fever, shortness of breath, and pressure in her chest. At the advice of her physician, she is transported to the nearest hospital which has no ICU capacity. A rapid test at the hospital indicates that she has COVID-19, and she is kept in a temporary isolated waiting area for an extended period as her condition deteriorates. Treatment is delayed until an ICU bed and ventilator are available. Her condition stabilizes, but she requires an extended hospital stay to recover.

Once she is stabilized, a public health investigator contacts her and tries to reconstruct where she had been and with whom she had been in proximity during her contagious period. However, over a week has passed since she first exhibited symptoms so attempts to trace her interactions at the grocery store and pharmacy are unsuccessful.

Illustration



Data Exchange & Process Steps	
1.	Individual engages primary care provider (PCP) for diagnosis and specimen collection and testing
2.	PCP sends specimen to lab for testing
3.	While awaiting test results, the individual's condition worsens and she is brought to the nearest hospital, admitted, and diagnosed with COVID-19
4.	Lab transmits results to the (a) individual, (b) provider, & (c) applicable public health agencies
5.	Providers transmit reportable disease reports to applicable public health agencies; public health agency to follow-up for contact tracing
6.	Individual's admission data is transmitted to the Data Exchange Entity (PCP may not be connected)

**Data Exchange Entity may include a HIO, national network, EHR vendor network, or other data exchange entity*

Illustration Actors and Roles

Actor	Roles Specific to the Example
Individual	<ul style="list-style-type: none"> • Presents symptoms and/or provides specimen
Primary Care Provider	<ul style="list-style-type: none"> • Documents symptoms • Orders tests • Diagnosis conditions • Provides advice and/or treatment based on symptoms, complaints, diagnosis and/or test results • Transmits information for reportable conditions to applicable public health agencies • Prescribes medications and/or administers vaccinations

Actor	Roles Specific to the Example
Hospital	<ul style="list-style-type: none"> • Documents symptoms, test results, and care administered • Collects specimen • Provides treatment based on symptoms, complaint, diagnosis, and/or test results • Transmits information for reportable conditions to applicable public health agencies • Collects and transmits information on capacity (e.g., ICU, ventilators, available beds)
Laboratory	<ul style="list-style-type: none"> • Collects and analyzes specimens • Reports results for reportable conditions to applicable public health agencies and ordering physician
Public Health Agency	<ul style="list-style-type: none"> • Collects, records and tracks public-health related information including lab results and diagnoses for surveillance, contact tracing and other epidemiological information for research • Transmits data to county, state, and federal authorities as applicable • Establishes and communicates prevention, treatment, and vaccination guidelines • Administers vaccine distribution

3. Key Challenges

The COVID-19 pandemic and response revealed the fragmentation of our health data infrastructure to support public health responses. The speed, scale, and impact of COVID-19 illuminated weaknesses in the ability to scale and adapt systems to identify, monitor, contain, and respond to a rapidly emerging infectious disease. Specific data-related challenges included:^{20,21}

1. Gaps in Data Infrastructure and Exchange Capabilities: Many types of public health data are collected and transmitted via paper-based, phone, fax, or other non-machine-readable formats. Information may be re-keyed or manually reported which result in errors and transmission delays of critical information.²² In addition, challenges remain in connecting and linking information. For example, vital records are not completely linked to laboratory data, clinical data, medical examiner/coroner data systems, or case reporting systems. And CalREDIE and the California Immunization Registry (CAIR) systems were not designed to connect, consume, and incorporate health information from HIOs or directly from EHRs at the scale needed to tackle a global pandemic. PH reported information also often lacks basic demographic, occupational, and SDOH information. For

²⁰ Frohlich, Jonah, et al. Why California Needs Better Data Exchange: Challenges, Impacts, and Policy Options for a 21st Century Health System. California Health Care Foundation. March 2021.

<https://www.chcf.org/wp-content/uploads/2021/02/WhyCaliforniaNeedsBetterDataExchange.pdf>

²¹ APHL, ASTHO, CSTE, HIMSS, NACCHO, and NAPHSIS. \$450M Data Modernization Initiative Letter to Congress. July 2020. <https://astho.org/Federal-Government-Relations/Correspondence/PH-Orgs-Request-450-Million-for-CDC-Data-Modernization-Initiative/>

²² Ibid.

example, the COVID Equity Dashboard currently shows 20% of reported COVID cases lack race/ethnicity information.

2. Absence of Key Data Types: Basic clinical data (e.g., symptom, progress notes, vital signs), hospital/ED alerts, capacity emergency departments, acute care beds, ICUs, protective personal equipment, demographic information (race, ethnicity, sexual orientation and gender identity), and social information (occupation, living conditions, etc.) are stored in a variety of systems that are not easily electronically shared with public health departments and other stakeholders.

3. Complex data exchange rules and regulations: Navigating complex data exchange regulations and patient consent requirements can be difficult to obtain and manage, particularly during a pandemic which necessitates rapid responses to contain and manage outbreaks and toxic exposures.

Scenario 6: Coordinating Reentry Health Services

1. Description

Addressing the health and social needs of individuals as they transition from incarceration back into their communities.

2. Current State and Illustrative Example

The transition (or “reentry”) from incarceration to the community can be challenging. Individuals released from incarceration must reintegrate themselves with their families and communities while addressing a range of issues including potentially securing housing, care coordination, navigating access to health services, and finding employment. Incarcerated individuals have significantly higher rates of disease than the general non-incarcerated population and tend to suffer in greater numbers from infectious disease, mental health problems, substance use and addiction.^{23,24} Upon reentry, prompt and continuous coordination and management of health and social needs is complicated by health insurance coverage gaps, finding primary care physicians and specialty providers (particularly behavioral health), making health care appointments, locating and securing needed social service supports, and refilling prescriptions.²⁵

Through CalAIM, Medi-Cal eligible individuals transitioning from jails, state prisons and youth correctional facilities will have access to coordinated physical health, behavioral health and Community Services upon release (and in some instances while still incarcerated) to support their successful transition to the community. Successful re-entry depends upon the ability to collect, store and share information in a timely fashion among incarceration facilities, providers, social service agencies that support:

- (1) Accurate and timely screening, assessment, and support processes that begin prior to release;
- (2) Development of multi-sector community-based collaborations, and
- (3) Integrated and coordinated care models that link individuals to the full range of physical and behavioral health and social services they need as they transition back into their communities.

²³ Cloud, David H., Jim Parsons, and Ayesha Delany-Brumsey. "Addressing Mass Incarceration: A Clarion Call for Public Health." *American Journal of Public Health*. 2014, pp 389-391.

²⁴ American Academy of Family Physicians. *Incarceration and Health: A Family Medicine Perspective*. April 2017. <https://www.aafp.org/about/policies/all/incarceration.html>

²⁵ Ibid.

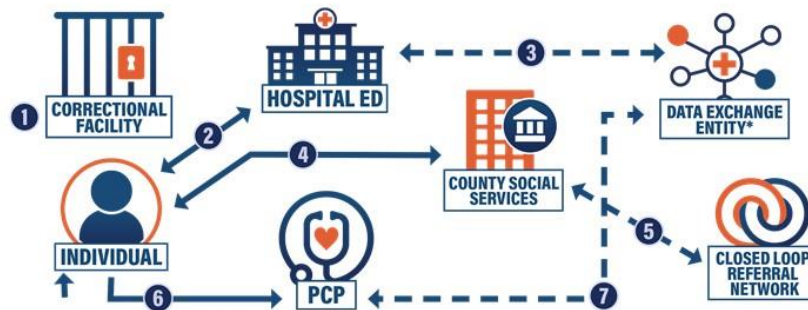
Illustrative Example

A 25-year-old white male in a county jail prepares for his release and transition back into the community. Prior to incarceration, he was diagnosed with hypertension and mild depression. Upon his release he is provided with medication to address his hypertension and depression, but he lacks health coverage and is unable to schedule an appointment with his primary care provider to assess and address his clinical and behavioral health conditions and medication needs. Prior to his doctor's appointment, he begins to feel chest pains and goes to the emergency department. While being admitted, the hospital is able to locate and obtain his medical records from a regional HIO, but the HIO does not have access to his medical history, diagnosis, and treatment while he was incarcerated and the information available from the HIO is out-of-date.

Upon release, he also contacts a County social worker to help him enroll in insurance and locate needed social services. The social worker consults a directory of CBOs and county-based agencies to refer him to organizations that can help him address his housing, employment, transportation, and food and nutrition needs.

The stress of his recent hospitalization exacerbates his depression. He contacts a primary care provider to get referral to a psychiatrist. The primary care provider is also connected to the regional HIO, but like the hospital, the primary care provider does not have access to the physical, behavioral health, and medication information during his incarceration. Critical medication reconciliation and updates to his prescriptions are delayed until he is able to secure an appointment, by which time his depression has worsened to a critical state.

Illustration



Data Exchange & Process Steps

1. Individual is released from the correctional facility
2. After the individual is released from the correctional facility, his condition worsens and he visits the hospital emergency department (ED) for treatment
3. Hospital ED queries regional data exchange entity for available health data (correctional facility's health information not available)
4. Individual engages county social service department for help accessing insurance and SDOH services
5. County social service representative queries CBO directory to identify support services for individual
6. Individual engages a new PCP to discuss worsening behavioral health condition
7. PCP queries regional data exchange entity for recent information on individual's health service utilization (correctional facility's health information not available)

**Data exchange entity may include a HIO, national network, EHR vendor network, or other data exchange entity*

Illustration Actors and Roles

Actor	Roles Specific to the Example
Individual	<ul style="list-style-type: none"> • Presents symptoms and seeks care
Correctional Facility	<ul style="list-style-type: none"> • Documents and records individual's health-related information
Hospital	<ul style="list-style-type: none"> • Treats individual's heart conditions
Primary Care Physician	<ul style="list-style-type: none"> • Treats individual's chronic and acute conditions • Exchanges clinical data with HIO
City, County and Other Public Agency Departments	<ul style="list-style-type: none"> • Provides information and referral to social and CBO services to address SDOH-related needs
Health Information Organization (HIO)	<ul style="list-style-type: none"> • Exchanges clinical and information
Closed loop referral network	<ul style="list-style-type: none"> • Provides information on SDOH-related services

3. Key Challenges

The following challenges were identified for this Scenario:

1. Limited Data Exchange: Data on justice-involved individuals is highly siloed across settings which creates barriers to collaboration and effective care coordination. Some justice-settings do not store and manage clinical and social service data in certified EHR technology, and these data are often not shared with other County agencies and community health and social service provider partners. In some cases, limited information is shared with consent from the individual, though this is not consistently obtained. In many cases where referrals

have been shared from State prisons, very limited information is shared – typically just demographic and release date information.

2. Absence of Key Data Types: National networks, HIOs, and EHRs generally have limited capabilities to exchange mental health and SDOH data that would help individuals reentering their communities to identify, obtain and utilize mental health and SDOH-related services. Closed loop referral networks and emerging community information exchanges (CIEs) efforts (e.g., Alameda County Care Connect and CIE San Diego), which support the sharing of non-clinical SDOH data, are showing promising results. However, CIEs currently operate in only a few communities in California, and they are not widely available to support important pre-release and reentry planning and coordination efforts.

3. Complex Data Exchange Rules and Regulations: Criminal history privacy laws typically assume that such information will be used for criminal justice purposes and for background checks, not to help a person find services such as housing.²⁶ Unlike federal law, California law does not permit the disclosure of criminal record data for purposes of coordinating care.^{27,28} While federal law is ambiguous on this point, California law is more clear in that disclosures for treatment purposes may be sent only to “providers of health care, health care service plans, contractors [generally independent practice associations or pharmacy benefit managers], or other health care professionals or facilities.”²⁹

²⁶ Dworkowitz, Alex and Cindy Mann. Data Sharing and The Law: Overcoming Healthcare Sector Barriers to Sharing Data on Social Determinants. Manatt Health. July 2020.

https://sirenetwork.ucsf.edu/sites/default/files/2021-02/Data%2520Sharing%2520and%2520the%2520Law_July%25202020_.pdf

²⁷ Cal. Penal Code §§ 11105, 13300.

²⁸ Note: release dates and booking data are among the more important data points for the provision of health services, and may be subject to different data sharing requirements

²⁹ Cal. Civ. Code § 56.10(c)(1).

Glossary

Actors

Potential scenario actors include, but are not limited to:

1. Individuals
2. Primary Care Providers
3. Specialty Physicians
4. Behavioral Health Providers
5. Hospital
6. Community Clinic
7. Alternative Care Facility
8. Emergency Response Providers
9. Ancillary Services
10. State Gov't Dept
11. City, County and Other Public Agency Departments
12. Correctional Facility
13. Public Health Agency
14. Managed Care Plans and Other Payers
15. Clearinghouse
16. Management Services Organization
17. Accountable Care Organization
18. Community Based Organization
19. Health Information Organization
20. Community Information Exchange
21. National network
22. EHR vendor network
23. Closed loop referral network
24. Specialized clinical data exchange network

Data Types

Potential scenario data types include, but are not limited to:

1. Demographic Data (e.g., race, ethnicity, sexual orientation, and gender identification)
2. Physical Health Data
3. Behavioral Health Data (e.g., substance use disorder and mental health data)
4. Immunization Data
5. Medication Data
6. Claims and Encounters
7. Lab Data (e.g., orders and results)
8. Event Notifications/Alerts
9. Care Plans
10. SDOH
11. Public Health Data
12. State Health and Social Service Program Indicators/Flags (e.g., Medi-Cal, SNAP, TANF, WIC, etc.)
13. Entity Directories
14. Quality and Outcome Data
15. Electronic patient care report (ePCR) data